

**MINUTES
of the
SECOND MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**September 25, 2015
Community Room, Adelante Development Center
3900 Osuna Road NE
Albuquerque**

The second meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee was called to order on September 25, 2015 by Senator Nancy Rodriguez, chair, at 8:55 a.m. in the Community Room at Adelante Development Center in Albuquerque.

Present

Sen. Nancy Rodriguez, Chair
Rep. Miguel P. Garcia
Sen. Linda M. Lopez

Absent

Rep. Tim D. Lewis, Vice Chair
Sen. Craig W. Brandt

Advisory Members

Rep. Deborah A. Armstrong
Sen. Gerald Ortiz y Pino

Sen. Ted Barela
Rep. Nora Espinoza

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Michael Hely, Staff Attorney, LCS
Nancy Ellis, LCS
Diego Jimenez, LCS
Erin Bond, LCS

Guests

The guest list is in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Friday, September 25

Welcome and Introductions

Senator Rodriguez welcomed those in the audience and asked subcommittee members and staff to introduce themselves. She then introduced Mike Kivitz, president and chief executive officer of Adelante Development Center, Inc., who described his nonprofit as a vital community resource and the largest supportive employment agency in the state (see handouts). Adelante also conducts a number of programs that provide a "meaningful day" in the community for disabled New Mexicans and that include Desert Harvest, a rescued food pickup; the operation of the Benefits Connection Center; and a "Back In Use" program that provides free, refurbished durable medical equipment. Mr. Kivitz said Adelante has scaled back its services as a developmental disabilities (DD) waiver provider because reimbursement rates are not sustainable, with Adelante reporting program losses of \$2.5 million last year. The state needs to increase provider rates, Mr. Kivitz said, because without that increase, Adelante cannot do its job.

Representative Armstrong congratulated Mr. Kivitz, noting that Adelante just received an award as Nonprofit of the Year from Albuquerque Business First.

Litigation Update

Tim Gardner, legal director, and Jason Gordon, litigation manager, both with Disability Rights New Mexico, provided an update on litigation brought against the Human Services Department (HSD) in federal court regarding resource allocation for adult DD waiver recipients as determined by the Supports Intensity Scale (SIS). The lawsuit also addressed denial of due process reported by clients who tried to appeal their allocation. The court issued a preliminary injunction and ordered the Department of Health (DOH) to restore the previous level of services to adult DD waiver recipients. After many months of negotiation, a broad settlement agreement was reached and was approved by the court (see handout). Mr. Gordon described in detail the many changes to available services for DD waiver recipients and the appeals process. The Continuum of Care Project at the University of New Mexico (UNM) School of Medicine was chosen as third-party reviewer of new DD waiver budgets.

To carry out these changes, a special appropriation from the legislature will be needed, currently estimated at about \$9 million, according to Cathy Stevenson, director of the Developmental Disabilities Supports Division of the DOH. The SIS tool can still be utilized as a method of assessing client needs, she said, but not for determining what services a client will receive (see handout). The department will have more detailed financial projections soon and is scheduled to present on this before the Legislative Finance Committee next month. Angela Medrano, deputy director of the Medical Assistance Division of the HSD, said the agencies that are parties to the settlement agreement do not believe that the agreement will require an amendment to the state's Medicaid waiver, which comes up for renewal next June.

On questioning, subcommittee members and panel presenters discussed the following issues:

- a request of \$9 million in additional funding to be matched by other programs, totaling approximately \$24 million;
- concerns about budgeting for these restored services in the future;
- questions about the four- to six-member UNM team that will review new budgets;
- changes to notices denying or approving budgets to include justification;
- time lines to resolve disputes;
- the cost of new services that may affect efforts to reduce the DD waiver wait list; and
- difficulties within the system for dealing with DD consumers who also have behavioral health needs.

Update on Efforts to Abolish the Marriage Penalty

Marilyn Martinez, a consumer and disability advocate, was unable to attend the day's session, but Nat Dean, also a long-time advocate, described Ms. Martinez's tireless efforts to repeal the marriage penalty for persons on Supplemental Security Income (SSI), which penalizes two opposite-sex individuals who marry by 25 percent and also lowers by 25 percent the permissible asset limit (see handout). To get around this, a partner can sign a spousal refusal form refusing to pay for the other's debts, but this solution is abhorrent to many of the individuals who are affected. Ms. Dean thanked legislators for passing Senate Memorial 3 and House Memorial 15 during the last regular session urging every member of Congress, every governor and the president of the United States to repeal the marriage penalty. Because of extreme partisan gridlock, there is little hope of change in Washington, Ms. Dean said.

Special Needs Planning

Nell Graham Sale, a partner in Pregenzer Baysing Wideman & Sale, PC, in Albuquerque, is a trust lawyer who specializes in helping persons with special needs. For disabled individuals to access certain government benefits, they must impoverish themselves and remain poor in order to maintain those benefits, Ms. Sale explained, but special needs trusts can shelter additional resources for these individuals. The federal Achieving a Better Life Experience (ABLE) Act of 2014 allows eligible persons with disabilities diagnosed before age 26 to establish a tax-advantaged savings account to pay disability-related expenses while protecting eligibility for federal and other disability benefits (see handout). Deposits to an ABLE account may not exceed \$14,000 per year, and documentation must accompany qualifying disability disbursements. The ABLE Act requires each state to pass enabling legislation, and 27 states already have done so; in New Mexico last year, two such bills died during the regular session. Ms. Sale also described several types of special needs trusts: self-settled (sheltered from being counted as a resource); payback (upon death of the disabled individual, the state has the right to recover any of its costs); and third-party settled trusts (see handout). Ms. Sale also explained how reforms of the federal Patient Protection and Affordable Care Act (PPACA) affect medical coverage for persons with disabilities and described other federal legislation that protects survivor benefits for disabled children of military veterans.

On questioning, subcommittee members and Ms. Sale discussed the role of the state's Medicaid recovery program with regard to special needs trusts, as well as current plans to move forward with ABLE legislation in the state's next legislative session. Ms. Sale emphasized that trusts should be considered an essential building block in providing care for persons with disabilities.

Motion for Recommendation to Full Committee

The subcommittee unanimously approved a motion to recommend to the full Legislative Health and Human Services Committee the endorsement of enabling ABLE legislation.

Autism Update

Lori Unumb is an attorney from South Carolina who, with her attorney husband, started a scientific nonprofit research center, the Autism Academy of South Carolina, after her son was diagnosed with autism before his second birthday (see handout). Today, Ms. Unumb is vice president of state government affairs for Autism Speaks, teaches autism law at George Washington University and with her husband has co-authored a textbook on autism. Following her son's diagnosis of autism before age two, intense applied behavior analysis (ABA) therapy was recommended for him for approximately 40 hours per week. Autism is not curable, but it is treatable, Ms. Unumb emphasized. She showed a short video of a child receiving ABA therapy. This intense one-on-one therapy can change the trajectory of a child's life, she said, and it requires special education and training; the treatment modality can cost more than \$70,000 per year. Currently in New Mexico, there are only 32 board-certified behavior analysts, she said, leaving the state with inadequate resources for this highly effective therapy. Twenty-four states have created licenses for ABA behavioral analysts, and UNM has one program with a course sequence that leads to this certification.

In South Carolina, Ms. Unumb was the impetus behind the 2008 passage of South Carolina's Ryan's Law, named after her son, which mandates the inclusion in insurance of ABA therapy and other autism treatments prescribed by a treating physician up to a \$50,000 annual cap. Autism Speaks, headquartered in New York, advocates for nationwide reform in insurance coverage for autism, which is now in effect in more than 25 states. Coverage of ABA therapy has been mandated in 42 states, with New Mexico being one of the first. Ms. Unumb detailed the effects of the PPACA's mandated treatment of autism and compliance with mental health parity laws.

Kristin Sohl, M.D., associate professor of child health, University of Missouri Thompson Center for Autism, described a Missouri initiative utilizing the Project ECHO model to transform primary care for children with autism (see handout). Autism is on the rise, she said, with one in 68 children now being diagnosed with autism spectrum disorder. Early intervention reduces the long-term costs and improves outcomes. In Missouri, a state that did not expand Medicaid with the PPACA, there are 500 children on a waiting list for assessment, and it can take up to nine months to get an appointment. Dr. Sohl's program, funded by grants from Autism Speaks and the Autism Treatment Network, aims to train primary care providers (PCPs) to

recognize the disorder earlier, become more comfortable treating the medical conditions of children with autism, share best practices and help access services for children while they are waiting for assessment/treatment. ECHO Autism provides biweekly, two-hour clinics that connect experts to PCPs and has increased knowledge across multiple domains in a very rural state. The program also has been joined by sites in Minnesota, northern Arizona and southern Utah, and it recently received a federal grant from the U.S. Department of Health and Human Services' Health Resources and Services Administration for replication in hospitals throughout the country.

Pat Osbourn, M.A., director of the Autism and Other Developmental Disabilities Programs Division, Center for Development and Disability (CDD), UNM, described multiple programs of the division that provide direct services, technical assistance and capacity building (see handouts), as well as comprehensive evaluations, parent home-training and written materials and resources for families dealing with autism. She also provided a copy of the division's autism programs training calendar through June 2016. Ms. Osbourn said information is provided in English and Spanish, with funding for community-based programs coming from the DOH and the Public Education Department (PED). A new children's psychiatric hospital is being planned at UNM, and there will be a section specifically for children with autism, Ms. Osbourn said. New Mexico is getting better at recognizing autism, but improvement is still needed in screening.

Gay Finlayson, M.A., education and outreach manager for the CDD, provided a summary of autism initiatives in the New Mexico Legislature, beginning in 2007 and including details of an upcoming 2017 budget request for \$150,000 to the DOH to assist behavioral health providers and their adult autism clients who do not meet DD waiver criteria to access services through Medicaid (see handout). There are few services available for adults with autism, she said, and while these individuals are entitled to behavioral health services through Medicaid, the managed care organizations (MCOs) claim they are not required to provide them through comprehensive community support services.

Dauna Howerton, Ph.D., Behavioral Health Services Division, HSD, is in charge of contract management for the MCOs and is state lead on ABA services. The rule regarding ABA services within Medicaid is now five pages long, she said, and it details who can provide the services, their required professional qualifications and how improvement will be measured. Meetings are being held weekly; providers are being trained and asked to collaborate. Nothing is happening in isolation, Dr. Howerton said; the goal is for all MCOs to do the same thing.

Katie Stone, legislative chair of the New Mexico Autism Society, urged legislators to closely examine the PED's budget for special education spending and the state's maintenance of effort (MOE) requirements. The U.S. Department of Education recently won a lawsuit against the PED for past failures to meet this threshold, and the department's 2016 budget once again underfunds the MOE requirement (see handout), Ms. Stone asserted. Every disabled child is entitled to special education services, and New Mexico's efforts to underfund these services is shortsighted, as every dollar invested today is a savings for tomorrow when these children have

grown into adulthood. Legislators must dig deeper into the underfunding of special education in New Mexico, advised Ms. Stone.

On questioning, subcommittee members and panel presenters discussed the following issues:

- the availability of a statewide registry of children and adults with autism;
- making certain that state autism laws do not discriminate by age;
- a lawmaker's observation that carrying a bill for autism services is an opportunity to educate fellow legislators;
- the possibility that federal match funds for special education could be used to address adult autism issues;
- utilization of child-only policies on the insurance exchange to obtain coverage for needed autism services;
- the possibility of expansion of ABA training to additional New Mexico universities;
- seeking solutions "outside the box" to raise revenue for autism services; and
- finding innovative methods to help build the autism provider network.

Former State Representative Liz Thomson, a previous chair of the subcommittee, was recognized from the audience. Ms. Thomson is a physical therapist and also the mother of an adult son with autism. She addressed the estimate of \$10 million, suggested in earlier discussions, to be the amount currently needed for autism services in the state. It is not enough, she said; other states are so far ahead of New Mexico, and there is no real plan to address autism. She suggested that an autism task force be reimplemented. The children being neglected now will be around for a long time, she said; it is pay now or pay later.

Motion for Legislation

The subcommittee approved a motion that LCS staff draft legislation for subsidizing ABA training and education in order to expand its availability in New Mexico.

Presentation Postponed

Staff announced that the final presentation of the day, Centers for Independent Living, was being postponed until the next meeting in Santa Fe on October 22.

Public Comment

Anna Otero Hatanaka, executive director of the Association of Developmental Disabilities Community Providers, noted that her grandchild gets excellent special education services from Albuquerque Public Schools. Speaking on behalf of her organization's members, she urged that one reimbursement rate be utilized for all service systems instead of multiple different rates. All rates should be at the higher level that has been approved for members of the *Jackson* lawsuit class.

Star Ford, mother of a neuro-divergent child, said that many autistic individuals do not want to be "normalized". Society should not be talking about how much autistic individuals cost, she said, but should be focusing on what they can contribute and what can be done to make jobs accessible rather than what can be done to make them "fit in". Autistic individuals need independent representation in matters that relate to them, and it is the state's job to listen.

Zoe Migel, a social worker who specializes in helping families with autism, introduced a client who has a two-year-old autistic son and cannot get him into ABA services. Her son is still young and needs these services now, but she has been getting the runaround from providers and has been unable to secure any services. Ms. Migel urged that the state develop a program that would bring in providers from other communities to support and bolster the behavioral health network. She sought, and was granted, permission from the chair to read from a stack of letters provided by her clients, including ones from:

- a mother whose son was diagnosed with autism in 2014, does not talk and needs ABA but who has been on a wait list for six months;
- a parent with an autistic child from the Pueblo of Santo Domingo who cannot find an ABA provider in the region;
- a parent who could not find ABA services in Santa Fe and whose treatment is being denied because there are no providers;
- a mother from Pojoaque who was referred by her MCO to two different companies for ABA, neither of which provide those services; and
- a state employee whose child was on a wait list for diagnosis but was able to receive services through the Family Infant Toddler program. Today, he is in a charter school and has been mainstreamed in second grade. It is nearly impossible to find ABA services outside of Albuquerque, the state employee said, and many families do not have the support system or resources to persevere.

Minutes Approved

Minutes from the August 28 meeting of the subcommittee were approved.

Adjournment

There being no more business before the subcommittee, the meeting was adjourned at 4:05 p.m.